

# MENTAL RETARDATION

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## **Introduction**

Mental retardation is not a single, isolated disorder. It is a term used to describe a condition affecting individuals who are limited in mental functioning to a level that affects many aspects of life, including basic skills such as communicating, taking care of personal needs, and social interaction. The national prevalence rate for mental retardation has been cited at 1.1% (Kerker, as cited by the Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services, 2003). Mental retardation is approximately 1.5 times more common in boys than in girls (Silka & Hauser, 1997).

The following information is specific to Virginia and was obtained from the Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS). According to Shirley G. Ricks, Director of DMHMRSAS' Office of Child and Family Services, national prevalence estimates applied to 2000 Census Data for Virginia indicate that 1.2% of Virginia's population (or 11.8 cases per 1,000) have mental retardation (Personal Communication, July 19, 2005). Based on the prevalence rate, it is projected that 14,166 children in the Commonwealth have mental retardation. The Virginia Department of Education data indicates that there are 13,975 children between the ages of 3-22 with mental retardation being served by the school system. In 2004, data from Virginia's community services boards indicated that 10,973 children between the ages of 0 to 17 having a diagnosis of mental retardation were being served (Personal Communication, July 19, 2005).

Mental retardation originates before the age of 18 (DMHMRSAS, 2003). The first signs of mental retardation are usually displayed in early childhood, often within the first or second year of a child's life. The child tends to lag behind his peers in milestones such as sitting up, walking, and talking. He also demonstrates lower than normal levels of interest in his environment and responsiveness to others (*Gale Encyclopedia of Childhood and Adolescence*, 1998). The existence of limitations in adaptive skills occurs within the context of community environments, typical of the child's age and is based on individualized needs for supports (DMHMRSAS). It is important that parents, pediatricians, and service providers are familiar with and recognize these signs, as early intervention serves as a crucial component to ensure that the development and quality of life of these children are maximized.

The *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)*, published by the American Psychiatric Association, provides the standard criteria for a diagnosis of mental retardation which are used in the diagnosis of children, as well as adults. The disorder is characterized by “significantly subaverage intellectual functioning” which must be supported by three factors: intellectual impairment, significant difficulty in adaptive functioning, and onset before the age of 18 (American Psychiatric Association, 1994).

The first required element of the diagnosis—intellectual impairment—is typically measured by cognitive testing instruments. Normal intelligence (IQ) measurements on standardized, individually administered tests, such as the Wechsler Intelligence Scale or the Stanford-Binet test, generally fall between 80 and 135 and, for this diagnosis, the child must have an IQ that falls below 70 or 75 (Szymanski & King, 1999). The threshold for mental retardation is typically set at 70, and experts generally agree that scores of 71 to 75 are consistent with mental retardation only when significant deficits in adaptive behavior are present (Szymanski & King). Normal IQ measurements on these tests generally fall between 80 and 135.

In addition, all children receiving the diagnosis must also demonstrate significant impairment in two or more of the following adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work (American Psychiatric Association, 1994). There are standardized scales to measure these behaviors, but they often do not capture all of the functional domains, and therefore this element of diagnosis is typically measured after a clinical assessment of the child (Szymanski & King, 1999).

A diagnosis of mental retardation has been further classified based on the child’s level of impairment. Table 1 outlines *DSM-IV*’s degrees of severity of mental retardation.

Table 5

**Degrees of Severity of Mental Retardation**

Mild mental retardation	IQ level 50-55 to approximately 70
Moderate mental retardation	IQ level 35-40 to 50-55
Severe mental retardation	IQ level 20-25 to 35-40
Profound mental retardation	IQ level below 20-25

Source: *DSM-IV*, 2000.

The *DSM-IV* also stipulates that the onset of symptoms occurs prior to the age of 18. It is important to note, however, that experts warn that children under age two should not be given a diagnosis of mental retardation unless the deficits are relatively severe and/or the child has a condition that is highly correlated with mental retardation, such as Down syndrome. Instead, service providers should acknowledge the cognitive or behavioral deficit as a form of developmental disability and leave room for further diagnosis as the child gets older (Biasini et al., in press; Sattler, 1992).

In recent years, there has been an effort to replace the term “mental retardation” with “intellectual disability” (American Association on Intellectual and Developmental Disabilities, 2007). Both the Centers for Disease Control and the American Association on Mental Retardation have adopted the

term (American Association on Intellectual and Developmental Disabilities). In addition, the President's Committee on Mental Retardation has adopted the change in renaming the committee the President's Committee for People with Intellectual Disabilities [PCPID] (President's Committee for People with Intellectual Disabilities, 2007). However, the term "mental retardation" continues to be used in the *DSM-IV* (American Psychiatric Association, 1994). In Virginia, the agency responsible for serving this population, the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) continues to use the term "mental retardation". Furthermore, some readers may not be aware of the term "intellectual disability". For the purposes of this Collection, "mental retardation" is used.

## **Causes and Risk Factors**

There are numerous causes of mental retardation. Those most frequently cited include external factors, such as infections, trauma, toxins, premature births, and delivery problems. Down syndrome, Fragile X syndrome and fetal alcohol syndrome (FAS) together are responsible for 30% of all identified cases (Jellinek, Patel, & Froehle, 2002). An estimated 300 genes are believed to play a role in mental retardation, while only 11 genes responsible for mental retardation are not associated with named syndromes, e.g., Down syndrome (Kingman, 2002). In about a third of people with mental retardation, no cause for that retardation has been found (*Dallas Morning News*, 2002).

A deficiency of a key protein called WAVE-I, found throughout the brain, may correlate with one form of mental retardation (Pain & Central Nervous System Week, 2003). Findings from the study cited indicate that mental retardation involves many more areas of the brain than previously determined (Pain & Central Nervous System Week).

It is important for the causes of retardation to be identified, if possible, in order to clarify the prognosis and tailor treatment efforts (Szymanski & King, 1999). Furthermore, the identification of causation may be valuable in alerting the clinician to possible medical and behavioral complications that occur more frequently in certain conditions (Szymanski & King). However, research has shown that in 58 to 78% of the cases of mild retardation and in 23 to 43% of severe cases, no official cause has been determined (Szymanski & King). The milder the mental retardation, the more difficult it is to identify the etiology (Jellinek, Patel, & Froehle, 2002).

A multidisciplinary team that may include psychologists, psychiatrists, pediatricians, and clinical geneticists typically conducts the assessment for mental retardation. All assessments should be comprehensive and should include standardized intelligence testing, evaluation of adaptive skills through testing or clinical evaluation, biomedical and family history evaluation, and psychological and behavioral testing (Szymanski & King, 1999).

## **Comorbidity**

Individuals who receive a diagnosis of mental retardation frequently suffer from additional mental disorders (Masi, 1998). Clinicians and researchers have explained this high prevalence of co-morbidity as the result of the psychological vulnerability of children with mental retardation. This can have a significant impact on a child's coping skills and mental health, and it may be one of the primary factors limiting the functioning, quality of life, and adaptation of mental retardation to community life (Masi).

The prevalence of mental illnesses in children with mental retardation ranges from 27 to 71% (Bregman, 1991). There is a substantial range of variation in the prevalence rates found in prior studies due to differences in methodology, diagnostic definitions, and population sampling strategies among the different studies. Frequently, the symptoms of mental retardation may disguise the symptoms of any co-occurring disorders (Rifkin, 2004). The most common comorbid conditions are described in more detail in the following paragraphs:

- *General Medical Conditions* – Seizure disorders are present in 15 to 30% of individuals with severe or greater mental retardation, and motor handicaps (20 to 30%) and sensory impairments (10 to 20%) are also frequently reported (Szymanski & King, 1999).
- *Pervasive Developmental Disorders* – Mental retardation is extremely common in children with pervasive developmental disorders. Approximately 75% of autistic children are also diagnosed with mental retardation (Fombonne, 1997). However, a reciprocal relationship has not been reported; the majority of children with mental retardation do not display significant impairments in reciprocal social interaction that are typically present in pervasive developmental disorders such as autism.
- *Attention Deficit Disorders (ADD and ADHD)* – The incidence of Attention Deficit Disorder (ADD) is more frequent in persons with mental retardation (18%) than in the general population (9%) (*DSM-IV*). Attention Deficit Hyperactivity Disorder (ADHD) is also particularly frequent, with a range of 4 to 11% of persons with mental retardation affected by this disorder (Feinstein & Reiss, 1996). Experts have attributed the frequency of these diagnoses in the mentally retarded to the fact that inattention is often a component of intellectual impairment.
- *Conduct Disorders* – It has been reported that approximately one third of children and adolescents with mental retardation display the characteristics of conduct disorder (Richardson et al., 1985). However, experts caution that it is important to consider the child's circumstances, ability to understand social rules, and possession of sufficient skills to communicate opposition when proposing such a diagnosis (Szymanski & King, 1999).
- *Behavior Disorders* – Children with greater degrees of mental retardation have been found to display increased aggressiveness, feeding disorders, stereotyped movements and self-injurious behavior (Masi, 1998). Self-injurious behavior is particularly common, with approximately 10 to 15% of persons with mental retardation displaying these characteristics (Oliver et al., 1987). The tendency to self injury is particularly common in certain mental retardation syndromes, such as Lesch-Nyhan, Prader-Willi, as well as in patients with mental retardation who experience mood disorders (depressive and manic), schizophrenia, personality disorders, and anxiety disorders (especially obsessive-compulsive disorder) (Masi).
- *Mood Disorders* – Mood disorders, especially of the depressive nature, are quite common in persons having mental retardation and are believed to be significantly underdiagnosed (Szymanski & King, 1999). Social isolation, stigmatization, and poor social skills put children with mental retardation at increased risk for depression (Reiss & Benson, 1985). The symptoms are often triggered by external stressful events, but ordinary life changes can also be responsible (Masi, 1998). Bipolar mood disorders are also present in the mentally retarded, but are more difficult to recognize. They have been found to involve dysphoria coupled with periods of irritability, aggressiveness, or self-injury, rather than the more typical manic episode (Masi).
- *Anxiety Disorders* – While it is likely that these disorders are highly prevalent in persons with mental retardation, they are believed to be underreported due to the difficulty diagnosing persons of limited intelligence (Masi, 1998). Research indicates that the most frequent manifestations of anxiety disorders in this population include acute episodes of anger, flight, and crying or

compulsions (repetitive, ritualistic behaviors) (Masi). Clinicians have found that psychosocial stress factors, including fragile self-esteem, fears of failing, and loss of caregivers are likely contributors to the psychological difficulties of this population (Szymanski & King, 1999).

- *Posttraumatic Stress Disorder (PTSD)* – PTSD is also believed to be significantly under-diagnosed in this population (Szymanski & King, 1999). Children with mental retardation are particularly vulnerable to abuse, given their high level of dependency and their tendency to want to please others, as well as lack of understanding of their rights. They may also be targeted because of their lack of communication skills, which may prevent reporting.
- *Schizophrenia* – The incidence of schizophrenic disorders has been found to be higher in children diagnosed with mental retardation than in the general population (Heaton-Ward, 1977). All forms of psychotic disorders have been identified in mentally retarded persons (Masi, 1998).

The diagnostic evaluation for psychiatric disorders is principally the same for patients with mental retardation, child and adult, as it is in the general population (Szymanski & King, 1999). It is important to recognize, however, that the psychiatric diagnostic assessment of children with mental retardation must be comprehensive and consider biological, psychological, and social contexts, rather than being merely a “medication evaluation” focused only on the choice of drug to suppress a disruptive behavior. Furthermore, any additional mental health diagnosis should be formal and specific, rather than a nonspecific description of “behavior disorder” or “challenging behavior.” It is important that the child’s assessment and resulting diagnosis demonstrate that he is ill, rather than merely “bad” or “noncompliant.”

There are certain specific limitations that affect the reliability of the dual diagnosis in children and adolescents with mental retardation. First of all, the level of communication skills that the child or adolescent exhibits is strongly related to the reliability of the diagnosis (Szymanski & King, 1999). Individuals with more severe cognitive limitations are less likely to be given a dual diagnosis than children with lower levels of impairment due to their inability to communicate their symptoms and distress (Borthwick-Duffy & Eyman, 1990). Evaluation of significantly impaired children requires the mental health assessor to depend on information provided by caregivers familiar with the child and on direct behavioral observations, which tend to be less informative and reliable.

The reliability of the diagnosis is also highly reliant on the availability of information regarding the biological, psychological, and social history of the child or adolescent (Biasini et al., 1999). The child’s history of behavior and symptoms are often crucial in making a diagnosis and, in the absence of this information, the evaluator is placed in the difficult position of making a diagnosis strictly on current symptoms and behavior without being fully informed of a child’s treatment history. This information is particularly crucial in the evaluation of children with profound and severe mental retardation. Many psychologists and psychiatrists rely heavily on biological markers, observable signs, and patterns of family psychopathology to diagnose these severely impaired children (Sturmey, 1995).

The strength and accuracy of a diagnosis are also directly affected by the experience and training of the clinician conducting the evaluation (Szymanski & King, 1999). It is crucial that the assessment be conducted by an individual specially trained in the evaluation and treatment of children with mental retardation. Furthermore, clinicians must recognize that there are often mismatches between the behaviors scripted in the *DSM-IV* for certain diagnoses and the symptoms presented in children with mental retardation (Biasini et al., 1999). These differences can lead to under-diagnosis; therefore,

evaluators must be comprehensive in their approach and think outside the usual formulas when diagnosing children with mental retardation (Sturmey, 1995).

## **Treatments**

The treatment of children with mental retardation is based on two guiding principles: normalization and community-based care (Szymanski & King, 1999). Normalization requires that children with mental retardation live under patterns and conditions of everyday life that are as close as possible to mainstream society. This is based on the premise that the life functioning of a child or adolescent with mental retardation will improve if they have adequate supports (Jellinek, Patel, & Froehle, 2002). The concept of community-based care flows directly from this principle, calling for the treatment and integration of children with mental retardation within the community to the maximum extent possible. No more than 10% of persons with mental retardation in this country have ever lived in institutional settings, and most can be found either living with their families or in community-based out-of-home placements such as foster care, group homes, and independent living programs (Szymanski & King). Service providers have found that, with proper services, the majority of children with mental retardation do well in the community. With appropriate personalized supports over a sustained period, the life functioning of the child with mental retardation generally will improve; however, mental retardation is a life-long disability (Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services, 2003).

The primary goal of service providers specializing in mental retardation is prevention, as there is no cure for the condition once the damage has occurred (Szymanski & King, 1999). Whenever possible, providers hope to prevent conditions that may result in mental retardation in children by educating women and families about the benefits of abstinence from alcohol during pregnancy and frequent child immunizations. Moreover, if an underlying condition that may lead to mental retardation has been identified in a child, providers focus on the treatment of that specific disorder in order to minimize potential brain injuries that could increase the risk of mental impairment. However, once a child has been diagnosed with mental retardation, providers begin to pursue early intervention, education, and ancillary treatments, such as physical, occupational, and language therapies (Szymanski & King, 1999). In addition, family support and other services are typically put into place to ensure that the child is receiving comprehensive care in the home, school, and community.

The methods and intensity of treatment are adapted as the child progresses in age. In infants, exercises and special types of play are used to provide sensory and motor stimulation and enhance development (Gale Research, 1998). All states are required by law to offer children with mental retardation early intervention programs from the time they are born. Once the child reaches the age of three, federal law requires that special education programs be made available for the child and family. These services concentrate on self-care, such as feeding, dressing, and toilet training, and also provide assistance with language and communication difficulties and physical difficulties. As the child gets older, the emphasis on special education programs changes to training in daily living skills, as well as academic subjects. Treatment efforts will also include medical care for any comorbid physical conditions, such as seizure disorders, motor handicaps, and sensory impairments, as well as treatment of any psychosocial dysfunction and comorbid mental disorders.

Several factors may influence the choice of treatment methods in children with mental retardation. First, the child's level of cognitive and communication skills may cause a service provider to adapt the method of treatment. For example, a child who lacks communication skills would be unable to benefit

from verbally based treatments such as psychotherapy; consequently, behavioral modification and educational accommodations would be more effective. Another consideration is the impact of any concurrent general medical disorders. An effective treatment plan requires that the service provider recognize the child's physical limitations and synthesize physical, developmental, and psychological needs and interventions (Szymanski & King, 1999).

Furthermore, the site of treatment may impact the methodology used. In most cases, outpatient settings are appropriate if the necessary services can be secured in the community. However, providers must be more cautious when placing children with mental retardation in inpatient treatment facilities. Clinicians have reported that not all of these facilities are familiar with needs of children with mental retardation and many are not equipped to provide these children with appropriate therapy, habilitative or recreational programs, and other necessary services (Szymanski & King, 1999). Consequently, placements must be carefully made after the provider has gained a wealth of knowledge regarding the services offered and the methods used by the facility.

An additional factor that can have a significant impact on treatment efforts is the willingness of the child and family members to participate and comply with the therapeutic plan. Education and ongoing support are essential, and detailed explanations must be given to family members to ensure that they understand all of the behavioral and pharmacological interventions that are being used to treat the child.

### ***Developmental and Educational Services***

All states are required by law to offer early intervention programs for children with mental retardation from the time they are born. Infant/toddler services can be home-based, center-based, or some combination of these two methods. The nature of the services is determined based on an assessment of the child and the family priorities. Under federal law, these considerations must be used to develop an Individual Family Service Plan (IFSP) for the child, which should include input from all parties participating in the intervention. This plan is usually developed and coordinated by a case manager who is available and acceptable to the family. The services that are provided in response to this plan may include assistive technology, intervention for sensory impairments, family counseling, parent training, health services, language services, nursing intervention, nutrition counseling, occupational therapy, physical therapy, case management, and transportation to services (Biasini et al., 1999).

As the child gets older, psychoeducational services must be provided. The Individuals with Disabilities in Education Act (IDEA) (Public Law 94-142, Public Law 99-457, and Public Law 102-119) requires that children with mental retardation or related developmental disorders receive a free and appropriate education. Interventions are based on the needs of the child as determined by a team of professionals. These interventions should address the priorities and concerns of the family and should be provided in the least restrictive and most inclusive setting, allowing them to have every opportunity to interact with nondisabled peers and to have access to the community resources available to all other children.

The services provided to preschool children and school-aged children can be home-based, but are more frequently center-based. As in the case of infants and toddlers, an Individualized Education Program (IEP) is developed through team evaluation and parental input. This plan describes the objectives for improving the child's skills and may include family or parent-focused activities. It may include special education services, child counseling, occupational therapy, physical therapy, language

therapy, recreational activities, school health services, transportation services, and parent training or counseling. These services must also be provided in the least restrictive setting possible, such as a regular preschool program, Head Start Center, or the child's home (Biasini et al.).

### ***Treatment of Comorbid Conditions***

The general principles of treatment are the same as those for children with other mental disorders. However, treatment techniques may need to be modified in order to adapt to the individual's developmental level, particularly regarding communication skills.

Two elements significantly affect the effectiveness of psychotherapy in children with mental retardation. First, the child must exhibit a sufficient level of communication skills in order for this type of therapy to be appropriate. Second, in order to maximize results, treatment must be implemented across settings (classroom, home, and other environments); and the therapist must collaborate with the other interested parties in the child's life, such as teachers, family members, and other service providers (Szymanski & King, 1999).

The most effective forms of psychotherapy are:

- *Individual therapy* – This type of intervention has been found to be beneficial for children with mental retardation with higher cognitive skills (Harris, 1995). It is best conducted by a therapist specifically trained in developmental disorders. Techniques and activities should be adapted to the child's chronological age and level of development (Szymanski & King, 1999).
- *Family therapy* – Research supports the benefits of family therapy for children with mental retardation (Harris, 1995). It typically focuses on the caregiver's identification and support of the child's strengths and independence, and the provision of opportunities for success. It may also include educational and emotional support components. The family should be seen as treatment team members, as they are essential to recognizing the child's strengths, avoiding guilt feelings and overprotection, supporting the child's pathways to independence, and providing opportunities for success. This form of therapy has also been found to be beneficial in assisting in locating resources, identifying entitlement for services and providing advocacy, empathy, and concrete advice in management of the child's disability (Szymanski & King, 1999).
- *Group therapy* – Therapeutic efforts in a group environment have been found to be particularly useful with adolescents who have relatively good verbal skills, as they often benefit from peer interaction and support (Szymanski & King, 1999; Harris, 1995). Multiple family group therapy has also been found to be beneficial, as it provides the family and child with support in a context similar to society at large (Szymanski & Kiernan, 1983).
- *Behavior modification* – Behavioral modification has been reported to be beneficial to children with mental retardation that lack social skills or demonstrate problem behaviors such as self-injury (Reiss, 1994). This intervention provides a consistent and structured framework for teaching appropriate behavioral patterns, as well as adaptive life skills. It should be generalized and consistent in all settings, such as home and school, and should focus on teaching appropriate skills and behaviors to replace maladaptive behaviors, rather than merely suppressing them (Szymanski & King, 1999). Behavioral interventions teach helpful ways to communicate, play, and work (Rifkin, 2004).



- *Social skills training* – Social skills training has also been found to improve the integration of children with mental retardation into the community (Hollins et al., 1994). Those who receive social skills training are taught effective social interactions and appropriate social behavior.
- *Cognitive therapy* – This form of therapy teaches children with mild retardation to recognize situations in which they get into trouble and to adopt alternative behaviors and solutions. It has only recently been adapted for use with children with mental retardation, and therefore research regarding its effectiveness is limited (Benson, 1992). The therapeutic goal would be to develop more reasonable goals, with care taken not to set goals that are beyond the patient's cognitive ability (Rifkin, 2004).

### ***Pharmacological Treatment***

The effects of medication on children with mental retardation are not generally different from those on the general population (Szymanski & King, 1999). However, certain issues related to pharmacology have been recognized exclusively in the mentally retarded population. For example, clinicians have found that medication is often prescribed to children with mental retardation for symptom suppression without being integrated into the overall treatment plan (Szymanski & King). The literature repeatedly advises that medication should not be used for the convenience of caregivers or as a substitute for appropriate services. An additional concern is that follow-up behavioral data is infrequently collected and providers often fail to monitor for side effects. This is especially important in mentally retarded populations, because these patients may be unable to report symptoms adequately.

While psychotropic drugs are not often used with children with mental retardation, they are most often prescribed in patients who exhibit disruptive behavior, including self-injury, stereotyped behaviors, e.g., hand or finger twisting, or complex whole body movements, and aggression (Szymanski & King, 1999). Recent research suggests that atypical antipsychotics may be a better first choice than typical antipsychotics because of the lowered risk of side effects (Rifkin, 2004). This must be considered in light of the fact that there are no studies that address the use of antipsychotics in patients who are aggressive and psychotic (Rifkin). It is important to note that no professional body has published drug guidelines for patients with mental retardation, thus thorough psychosocial assessment and treatment are important in the treatment of patients with mental retardation whether or not they receive drug treatment (Rifkin). Moreover, medications should be prescribed as they would be for the general psychiatric population, with special attention being paid to possible behavioral effects (Silka & Hauser, 1997).

### ***Discharge Planning***

As indicated by Silka & Hauser, appropriate discharge planning is crucial for children that may be placed in acute or short-term inpatient treatment (1997). Effective discharge planning strengthens the supports provided by an existing placement as it facilitates continued psychiatric care. Ideally, discharge planning, including plans for outpatient follow-up and the provision of any additional services, should commence early in the process. Early and continual contact with all community supports, from family to outpatient therapists, is imperative. Silka & Hauser outline questions to be addressed by the treatment team:

- Who is responsible for which service (case manager, family, agency, client, and others)?
- What is expected from this hospitalization?
- What are the minimal discharge criteria?

## **Unproven Treatments**

The effectiveness of diet restrictions in mentally retarded patients is generally not supported by research (Szymanski & King, 1999). This type of treatment includes vitamin and mineral supplements and various dietary restrictions, such as yeast and gluten-free regimens.

## **Other Important Treatment Elements**

### ***Cultural Considerations***

Any assessment of adaptive behavior focuses on how well children can function and maintain themselves independently and how well they meet the personal and social demands imposed on them by their cultures. Because various cultures may hold their own views regarding the level of functioning/skills expected of children of certain ages, clinicians must be culturally sensitive in diagnosing children with developmental delays and retardation. In addition, the sociocultural background and native language of the child should be considered in assessing intelligence and level of impairment (Szymanski & King, 1999).

### ***Family Involvement***

Service providers must make every effort to include the family in all aspects of treatment and planning. They must consider the level of knowledge and understanding of the family regarding the disability of the child, and must also be sure that the family is sufficiently informed of all service and treatment options. If professionals fail to acknowledge parents as partners in the process, they run the risk of alienating them in the process. This can result in a lack of interest or participation in necessary services. Thus, the knowledge and expertise families already possess about their child and their child's syndrome should be valued (Hodapp, DesJardin, & Ricci, 2003). Families of children with less common genetic syndromes become the experts on their child's disorder, frequently being the only ones with experience or knowledge of a particular syndrome (Fidler & Hatton, as cited by Hodapp, DesJardin & Ricci).

### ***Availability of Community Services and Supports***

The Arc, a non-profit organization which supports persons with mental retardation, has reported that approximately 200,000 individuals nationwide are on waiting lists for such essential supports and services as service coordination, housing, employment, in-home supports, early intervention, transportation, and respite care (The Arc, 1999). A report by the Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) shows that service availability for children with mental retardation is also a serious concern in Virginia. In its 2001 Comprehensive State Plan, the DMHMRSAS reported that 1,858 children and adolescents were on the waiting list for mental retardation services.

Research indicates that lack of services can exacerbate the problems of children with mental retardation, as it may allow for an increase in the severity of the disability or learning delays (The Arc, 1999). Furthermore, lack of services may also lead to greater dependence, isolation, and a decrease in self-esteem and productivity. Consequently, providers and policy makers must make every effort to identify these children and provide them with necessary services to ensure that they become productive members of society.

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### **Organizations/Weblinks - National**

#### **American Association of Intellectual and Development Disabilities** (*formerly American Association on Mental Retardation*)

4444 North Capitol Street, NW. Suite 846 - Washington, DC 22001-1512  
800-424-4688  
<http://www.aaidd.org>

#### **Council for Exceptional Children**

Division on Developmental Disabilities  
1110 North Glebe Road, Suite 300 - Arlington, VA 22201-5704  
703-620-3660, 866-915-5000 (TTY), 888-232-7733  
E-mail: [cec@cec.sped.org](mailto:cec@cec.sped.org)  
<http://www.dddcec.org>

#### **National Down Syndrome Society (NDSS)**

666 Broadway, Eighth Floor - New York, NY 10012-2317  
212-460-9330; 800- 221-4602  
<http://www.ndss.org>

#### **National Fragile X Foundation**

P.O. Box 190488 - San Francisco, CA 94119  
800-688-8765  
<http://www.fragilex.org>

#### **National Organization on Fetal Alcohol Syndrome**

900 17th Street, NW, Suite 910 - Washington, DC 20006  
202-785-4585 or 800-66NOFAS (666-6327)  
E-mail: [info@nofas.org](mailto:info@nofas.org)

#### **National Information Center for Children and Youth with Disabilities (NICHCY)**

P.O. Box 1492 - Washington, DC 20013  
800-695-0285 (Voice/TTY)  
E-mail: [NICHCY@aed.org](mailto:NICHCY@aed.org)  
<http://www.nichcy.org>

#### **Special Education Resources**

<http://www.specialednet.com/Resources.htm>

**The Arc of the United States** (formerly Association for Retarded Citizens)

1010 Wayne Avenue, Suite 650 - Silver Spring, MD 20910

301-565-3842

<http://www.thearc.org>.

**U.S. Department of Education**

U.S. Office of Special Education and Rehabilitative Services

400 Maryland Ave., S.W. - Washington, DC 20202-7100

202-245-7468

<http://www.ed.gov/about/offices/list/osers/index.html>

IDEA 1997 Statute on Implementing Regulations

202-205-5465 or 202-205-5507

<http://www.ed.gov/offices/OSERS/IDEA>

**U.S. Department of Health and Human Services**

Administration for Children and Families

Administration on Developmental Disabilities

Mail Stop HHH 300-F - 370 L'Enfant Promenade, SW - Washington, DC 20447

202-690-6590

<http://www.acf.dhhs.gov/programs/add>

**Virginia Resources**

**Partnership for People with Disabilities at Virginia Commonwealth University**

700 East Franklin Street, 10th Floor - Richmond, VA 23284

804-828-3876 or 800-828-1120 (TDD Relay)

<http://www.vcu.edu/partnership>

**Support for Consumer-Run Mental Health Programs in Virginia**

<http://www.vocalsupportcenter.org/valinks.htm>

**The ARC of Virginia**

2025 East Main Street, Suite 120 - Richmond, VA 23223

804-649-8481

E-mail: [thearc@arcofva.org](mailto:thearc@arcofva.org)

<http://www.arcofva.org>

**University of Virginia Health System**

Mental Retardation

<http://www.healthsystem.virginia.edu/internet/homehealth/retardation.cfm>

**Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services**

Office of Mental Retardation Services

P.O. Box 1797 - Richmond, VA 23219

804-786-1746

<http://www.dmhmrzas.state.va.us>

**Virginia Fragile X Resource Group**

<http://www.vafragilex.org/right.html>

**Virginia Office for Protection and Advocacy**

E-mail: [general.vopa@vopa.virginia.gov](mailto:general.vopa@vopa.virginia.gov)

[http:// www.vopa.state.va.us](http://www.vopa.state.va.us)

Richmond Office

1910 Byrd Avenue, Suite 5 - Richmond, VA 23230

804-225-2042 or 800-552-3962

TTY 804-225-2042 or 800- 552-3962

Virginia Beach Office

287 Independence Boulevard - Virginia Beach, VA 23462

757-552-1148 or 800-552-3962

Voice/TTY 757-552-1145